

# Pediatric Endocrinology Practice in Nigeria: Challenges and Way Forward

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## Abstract

The prevalence of endocrine disorders in children in Nigeria is not well known. Therefore the burden of these diseases is often overlooked as most cases are undiagnosed or diagnosed too late; and yet they constitute a significant cause of morbidity and mortality in children. There has been a paucity of Paediatric Endocrinologists, absence of laboratory equipments and even drugs for the treatment of these diseases are often not in stock. The desired attention these endocrine diseases should receive from both health care institutions and the government is lacking. Therefore, the aim of this review article was to highlight the challenges facing the practice of Paediatric endocrinology in Nigeria and to proffer a way forward to building a robust endocrine care services in health institutions in Nigeria.

**Keywords:** Challenges, endocrinology, paediatrics, way forward

## INTRODUCTION

Google and Google scholar search engines were used in gathering scholarly articles for this write up. Key terms that describes the challenges of Paediatric endocrinology practice were searched and the information used in the write up.

Paediatric Endocrinology is a subspecialty in Paediatrics that studies hormones and the glands that produce them as well as disorders related to these glands and their hormones in children and adolescents.<sup>[1]</sup> Therefore the Paediatric endocrinologists diagnose, investigates, treat and manages hormonal disorders such as diabetes, disorders of growth, thyroid function disorders, adrenals diseases, disorders of sexual development and/puberty, disorders of the Pituitary and Hypothalamus, Ovarian and testicular dysfunction, Obesity, Vitamin D/ Calcium and/Bone disorders as well as endocrine cancers.<sup>[1]</sup>

Nigeria, like other developing countries, has a very high prevalence of childhood infectious diseases (pneumonia, diarrhea, malaria, tuberculosis, HIV/AIDS etc) and malnutrition.<sup>[2]</sup> Therefore, emphasis, concern and resources have been disproportionately channeled to combating these diseases with little or no attention to the non-communicable diseases (NCDs).<sup>[3]</sup> Therefore the attention to these diseases in the paediatric age group especially endocrine diseases is

near zero. In the Nigerian National Strategic plan of action for the control and prevention of non-communicable diseases,<sup>[4]</sup> only Diabetes Mellitus and Obesity, as endocrine diseases, are mentioned among other endocrine diseases to be given priority attention to as NCDs. This further highlights the non-attention given to other endocrine diseases such as disorders of growth, thyroid function disorders, adrenals diseases, disorders of sexual development and puberty, etc.

In the last few decades, there is an observed dramatic increase in the prevalence of these hitherto rare diseases and the NCDs are estimated to account for 24% of total deaths.<sup>[5]</sup> Paediatric endocrine diseases or disorders will contribute to this mortality if attention is not paid to its control and prevention.

In developed countries, paediatric endocrinology is a well established subspecialty in Paediatric Medicine.<sup>[6]</sup> So much medical literature (clinical and research studies) are available in these countries.<sup>[6]</sup> Therefore, the burden of endocrine disorders is fairly well established and enough data exist on most of

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these diseases in these countries. On the contrary, in Nigeria specifically and most of Africa in general, this Paediatric subspecialty is still at its infancy stage.

Childhood endocrine disorders now constitute a significant cause of morbidity and mortality especially Diabetes Mellitus and Obesity.<sup>[6]</sup> The psychosocial problems of youths and adolescents with these conditions could range from mild mood changes to psychiatric illness (mainly anxiety disorders).<sup>[7]</sup> Most of these children lose their self esteem and have an impaired quality of life despite treatment of the endocrine diseases.<sup>[8]</sup>

Therefore, there is need for policy makers and health providers to begin to pay more attention to these conditions. Advocacy by Paediatric Endocrinologists to the government of Nigeria to pay more attention to these disorders is imperative, as early detection and treatment can help reduce the morbidity and mortality.

## THE CHALLENGES OF PEDIATRICS ENDOCRINOLOGY PRACTICE

### Personnel

The prevalence rates of paediatrics endocrine diseases are not well documented especially in low and middle-income countries due to lack of trained health professionals to diagnose and manage these diseases.<sup>[9]</sup> Therefore, in Nigeria and by extension Africa, many children die undiagnosed, or if diagnosed, they often do not receive quality treatment at the hospital because of lack of specialist care. There is also paucity of data on these important non communicable conditions due to this lack or virtually non-existent personnel.<sup>[10]</sup>

Apart from the Republic of South Africa, the number of personnel in Paediatric endocrinology in other African countries was pathetic until recently when training of Paediatric endocrinologist was commenced in the Paediatrics Endocrinology Training Centre for Africa (PETCA), Nairobi, Kenya. In Kenya, until the year 2007, there was only one paediatric endocrinologist.<sup>[9]</sup> Currently there are more than eight board certified paediatric endocrinologists in Kenya following this training. Senegal that had none before the training, now has 3 Endocrinologist, but all based in the capital, Dakar. Botswana that had none before the training now has two. Nigeria had only two paediatric endocrinologist before 1999 but now has more than 27, still courtesy of the Paediatric Endocrinology Training Centre for Africa (PETCA).<sup>[9]</sup> The programme, PETCA is jointly sponsored by World Diabetic foundation (WDF), the International Society for Paediatric and Adolescent Diabetes (ISPAD), and the European Society of Paediatric Endocrinology (ESPE) and has been responsible for the training of Paediatric endocrinologists for much of Africa.<sup>[9]</sup> The bulk of paediatric endocrinologists currently in Africa are graduates of this noble gesture by this societies. PETCA was launched in 2007 in Nairobi, Kenya, with a mission to provide and maintain high quality training, research, and clinical

practice in the endocrinology subspecialty to paediatricians from all over Africa.<sup>[9]</sup> A similar programme, the Paediatric Endocrinology Training centre West Africa (PETCWA) was also established in 2011 to reduce the pressure on PETCA and has so far trained 56 paediatric Endocrinologist.<sup>[11]</sup>

Lack of other trained staff to complement trained doctors in care of Paediatric endocrine diseases is another big challenge. Because of the increasing patient load, it is important to have trained Nurses, Dietitians, medical Psychologists, health/diabetic educators and others in the care of patients with paediatric endocrine diseases. The PETCA and PETCWA programmes are yet to incorporate the training of these health staff to complement the efforts of the trained endocrinologist when they return to their practicing hospitals. It is the hope of many trained fellows of the programme that this would be done soon. It is also hoped that the universities in the centre where these training programmes are being coordinated will take over the programmes when the sponsorship expires.

### LABORATORY

Lack of specialized screening facilities, equipment and laboratory support are other challenges militating against the practice of paediatric endocrinology.<sup>[10]</sup> The cost of equipments for hospitals in Nigeria and indeed Africa is so high especially when there are other contending issues of health. Most of the investigations or hormonal assays have to be sent outside of Nigeria before diagnosis can be made. Therefore the cost of the tests is so exorbitant for these patients/parents who are paying directly from their pockets. Many patients cannot afford these tests and makes the issue of diagnosis difficult. The available tests results from local laboratories are sometimes not correct or not in keeping with clinical findings because of inexperience with such investigations by the attending laboratory scientist. In this milieu of challenges, the patients/parents and doctors become frustrated as diagnosis cannot be confirmed for appropriate treatment to be commenced. The end result is that correct data concerning many of the endocrine diseases cannot be obtained or kept. Research work is therefore hampered.

Radiological investigations especially computerized tomography (CT) scan, Magnetic Resonance Imaging (MRI) are also often beyond the reach of many patients/parents in terms of cost.<sup>[12]</sup> Where they are available, expertise of the attending Radiologist may be limited. Often, there are no paediatric probes for ultrasonographic investigation of children. This hampers the making of a definitive diagnosis and therefore may affect management of the endocrine disease in question. For instance, a virilising adrenocortical tumour in the Adrenal gland may be missed by ultrasonography but will be seen in a CT scan or MRI, and will allow early surgical resection of the tumour. Also metastatic tumour spread to the chest, Liver and Bone by this tumour can be diagnosed with a CT scan or MRI and may change the surgical management of the disease.

### Late presentation

The myth of witchcraft causing diseases in Africa<sup>[13]</sup> coupled with poverty and illiteracy is one of the reasons that lead to late presentation to hospital. Diseases are believed to be caused by evil spirits and especially so with endocrine diseases. Because they cannot explain the basis of these conditions, they resign their fate to these supernatural forces as an explanation to the cause of these conditions. They cannot understand why a three year old should have features of puberty such as development of breast and pubic hair. Therefore by the time they have visited the “native healers” and the symptoms have not abated as they were told, they then may present in a health facility. For endocrine conditions that need urgent attention, it becomes difficult to do much. A child with ambiguous genitalia is often hidden by the parents until adolescence when it becomes traumatizing to the child to reverse the sex of rearing based on your investigations. During my training as an Endocrinologist in the PETCA programme in 2010, I attended to a patient in Aga Khan University Hospital, that the parents were ostracized from the community because the child had genital ambiguity. This can be a very big challenge as presentations to hospitals are often late. Parents tend to hide these patients and shield them from neighbors and general public.

The late presentation to hospitals also means there could have been complications before such presentation leading to increased morbidity and mortality; and further brings to bear the need of parent education to increase awareness among the public by healthcare advocates groups.

### Absence of referral networks

Many rural health centres or local hospitals rarely refer patients with conditions that cannot be treated in such centres. In a study of referral systems in Nigeria, Akande found that only 7.1% of patients were referred to a tertiary health centre from local hospitals and private hospitals.<sup>[14]</sup> The remaining 92.9% reported directly to the hospital without referral. There are no well structured referral systems in the chain of health care in the country. Also Traditional medicine practitioners do not have limits to the type of diseases to treat and do not know when to refer patients that are not responding to their treatment to the hospitals where such conditions can be treated. So, many endocrine diseases are not referred to appropriate hospitals with trained endocrinologists. This is a very big challenge as patients are denied access to useful diagnostics and therapeutics from lack of referrals.

### Treatment cost

Treatment of patients with endocrine disease is often difficult to get for various reasons. Parents cannot afford some of the drugs for treatment because of high cost and sustainability. For example, in my centre twice daily Insulin regimen cost about \$ 13 an ampoule and this may last a diabetic patient for only 3 weeks. Therefore, the parents of the child are burdened with spending approximately \$ 15 every month on the child's treatment. Meanwhile most of these parents are living on less than \$3 per day and may not be able to sustain the treatment.

The same is true for other treatments like Growth hormone therapy, GnRH analogues therapy etc. Sustaining treatment with these drugs becomes very challenging especially if treatment is for a long period or for life.

In most cases, these drugs are not available in Nigeria and they have to be sourced by the pharmacist from outside Nigeria. Drugs that are cheap in Europe automatically become expensive in Nigeria because of import duties charged on the drugs.

Storage of drugs is another big problem because of epileptic power supply in Nigeria. This can be so frustrating after spending so much money and the drug becomes ineffective following poor storage.

### Follow up visits problems

Most of the Endocrine conditions require follow up for a long period of time or for life. This can be a very huge burden for parents/patients as they are made to pay for consultation during such follow up visits. The distance to hospitals from patient's homes sometimes can be more than 300 km or even non-motor able. Sometimes, investigations are required during such follow-up visits and new drugs may be prescribed which parents have to buy. This causes exhaustion and frustration on the part of the parents. Therefore, they may in the course of treatment be lost to follow-up as is often the case. The endocrinologist therefore loses data on outcome of treatments and cannot contribute to the body of literature in the world.

### TRANSITION TO ADULT CARE

Transition of care is defined as the “planned purposeful movement of adolescents from child-centered to adult-oriented care” in a “process that attends to the medical, psychological, educational needs of young people as they transfer to adult-oriented care.”<sup>[15]</sup> The actual transition practices among health care professionals are far from optimal<sup>[16]</sup> and much more difficult in most hospitals in Nigeria. There is paucity of trained adult Endocrinologist in Nigeria to transfer these patients to in many hospital centers and one is at a loss how to continue the care of these patients who have become adults. After 16-18 years, patients are transferred to adult clinics depending on the rules in such hospitals. For example, optimal metabolic control and quality of life are the major goals in the care of children and adolescents with diabetes mellitus. This care is supposed to continue after childhood into adulthood and therefore need an adult endocrinologist to continue care. This is difficult where there are no trained endocrinologists or doctors to manage diabetes. The same is true of other lifelong endocrine conditions.

Also differences in style and practice patterns of pediatric and adult medical systems also hampers smooth transition to adult clinics.<sup>[15]</sup> Often, these patients run back to the paediatric endocrinologist with complaints of not having adequate attention in the adult clinics compared to when they were with the paediatric endocrinologist. This is one of the challenges in

my hospital. This challenge is worrisome and has caused these young people to opt out of care altogether, only to resurface in the medical system when they develop complications which may have been prevented. There is evidence that the process of transition from Paediatric to adult care leads to deterioration in health of adolescents with chronic health conditions.<sup>[15]</sup> Therefore many countries have transitional care programmes to prevent the deterioration of the health of these children.<sup>[15]</sup> There is no literature on transition care in Nigeria. There is therefore need to bridge this gap in the practice of paediatric endocrinology in this regard. Endocrine diseases are often chronic conditions requiring long term management. Therefore they pose serious physical, mental and emotional challenges which the attending Endocrinologist must confront in order to keep the child in good health.<sup>[7]</sup> Absenteeism from school following repeated admissions can also affect the psychological state of the child.<sup>[7,8]</sup> These usually affect the attendance to follow-up visits to the hospitals and also the smooth transition to adult endocrine clinics.

### Lack of Political Will

Lack of Political will to invest in health care is a huge problem in Nigeria and Africa in general. In 2007, 27 (51%) out of the 53 African countries spent less than US\$ 50 per person on health.<sup>[17]</sup> The African Heads of States and Governments commitment to allocate at least 15% of annual national budgets to health sector<sup>[17]</sup> is never met and Nigeria is no exemption. Most of the investment is on infectious diseases/programmes, [HIV/AIDS, Integrated management of Childhood illnesses (IMCI), Tuberculosis programmes etc] leaving the non-communicable diseases almost with no allocation.<sup>[17]</sup> These policies reflect even in our medical schools as endocrinology has not been given enough room in the medical curricula until recently. Policy makers in government are not aware of the enormity of the disease burden of endocrine conditions and therefore there are no efforts to acquire equipments and drugs for the diagnosis and treatment of endocrine diseases.

## THE WAY FORWARD

The following are ways of improving the practice of paediatric endocrinology in Nigeria if the morbidity and mortality from these diseases are to be minimized.

### Training of Personnel

There is need for concerted efforts by various hospitals to train doctors in this subspecialty of paediatric endocrinology. There should be a strategic actionable health policy plan encompassing research, training, and quality assured service in an effort to expand both access and quality of services. The diagnosis of these conditions is often missed because the symptoms are missed by general medical practitioners. Even when the diagnosis is suspected, the manner of evaluation is far from standard. In the same manner, support staff (nurses, Dietitians, medical Psychologist, etc) in the field of paediatric endocrinology should be trained to complement the doctors. On completion of training, office space, consulting rooms

should be made available. The staff should feel motivated and encouraged to work.

In addition, those that have been trained should continue to consolidate their knowledge through update conferences and retraining courses.

### Networking

Hospitals and doctors should build linkages with other centers/colleagues between and within countries where telemedicine and video-conferencing can be used in managing challenging cases. The African Society for Paediatric and Adolescent Endocrinology (ASPAE), the Society for Paediatric and Adolescent Endocrinology of Nigeria (SPAEN) have been in the frontiers in this regards. There are a lot of networking between these societies and ESPE and ISPAD in terms of mentoring, collaboration and training in Paediatric endocrinology.

### Laboratory support

Laboratory support is the backbone of the practice of endocrinology as diagnosis and follow-up is so much dependent on the results of such tests. Therefore advocacy to Medical Directors/private Laboratories to equip their laboratories to wide range of new tests needed in diagnosis of endocrine diseases will help with this challenge. Since hospital administration and services are under the government of Nigeria, advocacy to the federal and state governments should therefore be carried out by Endocrinologists groups concerning appropriating funding to purchase new diagnostic equipments like biochemical analyzers, MRIs, CT scan, ultrasound, etc for hospital laboratories. Also, advocacy for legislative framework for neonatal screening programmes including endocrine diseases such as congenital hypothyroidism and Congenital Adrenal Hyperplasia (CAH) should be done. To overcome the challenge of high cost of investigations, the author orders tests in "Piece meal" over some few months until the patient is fully investigated and diagnosis is made. So over a period of 3-6 months, a patient with disorder of sexual development can be fully investigated and a diagnosis made because parents pay for selected investigations for each month. This author suggests that this approach be adopted by doctors in resource poor countries in Africa like Nigeria where parents are not on health insurance and pay from their pockets.

The challenge of getting drugs for the various endocrine diseases can be very challenging as these conditions are rare and pharmacy stores are not stocking the drugs. Parents can be helped by the doctors and pharmacists by out-sourcing the drugs from within and outside Nigeria for these children.

### General education/awareness campaign

Many parents and the general public are not aware of the existence of endocrine diseases and if they know, they are not aware they can be treated. It is therefore important for health campaigns to be carried out to inform the public about these conditions. The television, radio, the print media and social media are all channels through which information can be given

out to the public. When I came back from my training as an endocrinologist, I was featured in my state television where I talked to the public about endocrine diseases and debunking the myth about these conditions. My clinic thereafter started to increase. It is said that knowledge is power, and therefore people will always seek treatment once they know the condition can be treated. The churches/mosque can also be avenues to educate people about endocrine diseases; it has been effective for me. Posters/fliers/pictorials containing information about endocrine diseases distributed in schools, markets, in city centers and villages can also be valuable in creating awareness of endocrine diseases. Telephone messages and social media messages can be informative as well.

When the public is well informed, delayed presentation of endocrine conditions will reduce and therefore morbidity and mortality will reduce.

### Research Publication

It is important for the Paediatric Endocrinologists and other doctors to publish interesting endocrine case reports and other researches in Paediatric endocrine disorders in both local and international journals. This will stimulate interest in the subspecialty and encourage further research in grey areas that would arise from such previous researches. This will contribute to the body of knowledge in Paediatric Endocrinology in the world as well document baseline and trends in Paediatric endocrine disorders in Nigeria and Africa in general. Already there are a high number of conference presentation (in Scientific Conferences of Endocrine Societies) and research output by the Paediatric Endocrinologists in Nigeria and Africa at large. It will be pertinent to establish a Nigerian journal of Paediatric Endocrinology where research work in Endocrinology will be reported for visibility in the scientific world.

### Advocacy

Using data generated in the hospitals, policy makers in government can be convinced to devote some more attention and resources to Paediatric endocrinology. Government can then begin to acquire equipments for laboratory, drugs and also train needed personnel to handle these conditions.

### Public-Private Partnership

The Public-Private Partnership (PPP) for health is a national policy adopted by the federal government of Nigeria in 2005 as a reform to address the deplorable national health profile.<sup>[17]</sup> Many governments in the world are turning to PPP to provide financing for infrastructure/equipment for efficient and effective health care delivery for her citizens.<sup>[18,19]</sup> Equipments for investigations and treatment and drug procurement can be achieved by this partnership and the profit is shared between government and the companies or agencies/firms. Some hospitals in Nigeria have already keyed into this arrangements which will in addition curb medical tourism abroad. This allows for the private sector (both locally and internationally) to build, operate, maintain and to replace this equipments to ensure continuing efficient and effective health care delivery. Therefore laboratory, radiological investigations

and treatments will be accessible and affordable within the locality of the patients.

### Referral network/Transition clinics

There is need for an organized referral system from primary, through secondary and tertiary health centres where these diseases can be handled. Traditional “healers” must be involved in the enlightenment so that they can refer these conditions when they see them. This way the delay in the management of cases especially the emergency ones will be reduced or eliminated. Transition clinics from paediatric to adult care should be well organized in such a way that the paediatrician should see the patients together with the adult physician for some months before the paediatrician withdraws completely. This will prevent dropout rates of adolescents from continuing care in adulthood.

### Psycho-social support

Psycho-social support from health care givers, Psychologist and diseases’ groups/organizations can help encourage newly diagnosed patients with these diseases to continue in the follow-up care. Patients are encouraged to join groups like the Diabetic group, Turners syndrome group, Down syndrome group, etc as the case may be.

### Political will

The government policy actors and programme managers must have the political will to deploy resources to these non-communicable diseases. The laboratory should be equipped and maintained in our hospitals. Drugs that are needed in the treatment of these diseases should be made readily available and affordable. Government can go a step further by subsidizing some of these treatments for the patients as some of the treatments are very expensive.

### Privatization of the National Health insurance scheme

For the author, this is considered the “mother of all” for the way forward in the practice of Paediatric Endocrinology and indeed health care in Nigeria. In Nigeria, the government runs the health insurance scheme, appointing politicians to the head of this scheme. Often times, corruption by the politicians cripple the agency with non-availability of drugs and non-payment of the Health Maintenance Organizations (HMO) and the health facilities/hospitals. There are accusations of fake drugs and equipments purchased to this health facilities by these corrupt heads. At the end, as is presently seen, the patient ends up still paying from his/her pocket. However, when renowned private health insurance firms with experience in health insurance are contracted, many Nigerians will have confidence to enroll and invest in it. This will certainly be the solution to our protracted health care challenges of planning, financing and smooth operation of our health care delivery.

### CONCLUSION

Whereas, endocrine diseases were regarded as rare, they now constitute a major source of morbidity and mortality. Paediatric Endocrinology has evolved and has come to stay in Nigeria.

The gap in knowledge, management and awareness of endocrine diseases is reducing courtesy of the training of more Endocrinologists in Nigeria and Africa in general. The conference presentation of these Endocrinologists in scientific conferences of Endocrine Societies and research output in scientific journals has been encouraging. Eventually the establishment of a Nigerian Journal of Paediatric Endocrinology will further put in perspective the activities of Paediatric endocrinology in Nigeria and Africa in general.

Creating awareness in the population and within government, provision of laboratory support, a good pharmacy and a robust health insurance structure will certainly advance the practice of Paediatric Endocrinology in Nigeria. Children with endocrine conditions will be the better for it if these measures are put in place.

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